

Resilience and Strain Questionnaire for Caregivers

(RESQ-CARE,
English version
of FARBE)



A questionnaire to assess individual resilience factors and stress factors in family caregivers within the counseling context.

Publisher

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This English version is a translated and modified version of the German questionnaire FARBE (Fragebogen zur Angehörigen-Resilienz und -Belastung), which was published by the ZQP in 2020.

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Preface

In 2020, the first edition of the German-language questionnaire 'Fragebogen zur Angehörigen-Resilienz und -Belastung' (FARBE) was published. In German, the acronym FARBE (English: color) expresses that the caregiving experience of many caregivers is not monotonous, but that there is a great variety underlying the individual caregiving situation – informal caregiving is not only gray, but can also be colorful!

The German version of the questionnaire is based on a comprehensive literature research, which is presented in the manual. For each item, the background and the underlying rationale are explained. In addition, the German version was psychometrically validated, which was published in an open access English language publication (Wuttke-Linnemann et al., 2021). The validation is based on the German version. For the publication, the items were translated into English by a professional translator.

Subsequently, the FARBE questionnaire received increasing attention – also internationally. Therefore, we decided to provide an official English-language version of the working material. In cooperation with the Ontario Caregiver Organization (OCO), we were able to adapt the English translation of the questionnaire to the language usage and experience of English-speaking caregivers. The English version is therefore not only a mere translation of the items, but rather can be seen as an enhanced version integrating cultural specificities. This is reflected in minor changes or additions to the wording of the individual items, but not in fundamentally new items.

The authors and the publisher

February, 2023



Summary

■ Purpose and use of the questionnaire

The questionnaire is designed to help professional counselors in the care context to assess family caregivers' needs in terms of counseling and support (i.e., On which themes does a family member need advice?) and to evaluate the overall burden on family caregivers (i.e., How critical is the care situation for the family caregiver?).

The tool can be used to identify

- family caregivers' resilience factors and stress factors
- family caregivers with a greater need for counseling on a preventive level
- individually important themes for counseling.

■ Construction of the questionnaire

The RESQ-CARE questionnaire is conceived according to a weighing scale model, based in psychobiological terms on the principle of homeostasis, with family caregivers' resilience factors and stress factors being weighed against each other. The questionnaire consists of four scales, two depicting resilience factors ("My strength-givers") and two depicting stress factors ("My strength-sappers"). In addition, there is a general scale covering basic sociodemographic information, which offers an overview of the family caregiver's living situation.

■ Evaluating the questionnaire and interpreting the results

To evaluate the questionnaire, first of all, a sum score is formed for each scale (Strongly agree = 3 points, Agree = 2 points, Disagree = 1 point, Strongly disagree = 0 points), which can range between 0 and 15. High scores on the resilience scales indicate high resilience and high scores on the stress scales indicate high stress. The scale on basic sociodemographic information only serves to provide orientation.

Based on the results of the individual scales, themes for counseling can be derived. Moreover, the ratio of resilience factors to stress factors is interpreted. Family caregivers with low scores on the resilience scales and high scores on the stress scales are especially vulnerable.



Background

Family caregivers are at risk of becoming sick themselves.

■ Family caregivers

Informal caregiving is a worldwide phenomenon. In Germany, for example, around 5 million people are officially deemed as requiring care, and the majority are cared for by family members at home. Approximately half of these family caregivers identify as the sole caregiver for their loved one (Statistisches Bundesamt, 2022). Family caregivers carry out a multitude of different care tasks – from organizational responsibilities to providing physically demanding support. On average, family caregivers devote 20.5 hours per week to caring for their loved one, while 20% even spend more than 40 hours per week on tasks related to caring (Adelman et al., 2014).

Given their situation, family caregivers are frequently exposed to chronic stress and are at risk of developing physical or mental illness themselves (Pinquart & Sörensen, 2003). As such, they have even been described as “invisible second patients” (Adelman et al., 2014; Brodaty & Donkin, 2009). Often, family caregivers have health problems or illnesses of their own (e.g., depression, musculoskeletal problems, symptoms of exhaustion, respiratory infections) (Gräbel, 1998) – although it remains unclear whether the increased care burden leads to poorer health or whether family caregivers with poor health are more burdened by their caregiving responsibilities (Chang et al., 2010).

Family caregivers differ in how they deal with care-related stressors.

However, family caregivers differ in how they deal with care-related stressors. While some suffer from stress and become ill themselves, others are able to maintain their health and well-being despite the care situation. These differences in dealing with care-related stressors have been linked to interindividual differences in resilient behavior (Dias et al., 2015). Resilience – or the psychological ability to cope – describes the ability to bounce back from stressful life events.

Nowadays, we know that in addition to reducing stress factors, the promotion of resilient behavior is highly important for quality of life and for preventing stress-related physical and mental illnesses in family caregivers (Joling et al., 2016; Palacio et al., 2019).

■ Resilience factors in family caregivers

So far, there is no uniform or definitive model on which factors contribute to resilience in family caregivers. Instead, there are a multitude of studies examining individual factors, which are in turn systematically classified in review articles.

In the context of family caregivers, the majority of research focuses specifically on family caregivers of people living with dementia. In these individuals, Dias et al. (2015) suggested

dividing resilience factors into the following dimensions: biological, psychological, and social. The authors thus follow the rationale of a biopsychosocial explanatory model, which is widespread in the health domain. For instance, they report that female family caregivers show higher resilience than do males (biological dimension), that lower depression scores are associated with higher resilience (psychological dimension), and that social support predicts higher resilience (social dimension). Joling et al. (2017) added an interpersonal dimension to this classification, which captures the quality of the relationship with the person living with dementia. While these studies refer to family caregivers of people living with dementia, it can be assumed that the biopsychosocial model can also be transferred to other diseases. An association between social support and higher resilience has indeed been consistently reported for other diseases (Kim et al., 2012; Hwang et al., 2018; Ong et al., 2018; Salim et al., 2019), although the majority of these studies are individual studies, and reviews to categorize the resilience factors are still lacking.

Resilience is a multidimensional construct and can be considered from the perspective of a biopsychosocial model.

■ Stress factors in family caregivers

At the opposite end of the spectrum to resilience factors are stress factors. Manifold studies have examined which factors lead to stress in family caregivers, leading to the identification of factors relating to a) the care recipient him/herself (e.g., severity of illness), b) the family caregiver (e.g., self-efficacy expectation, basic attitudes), and c) the living situation (e.g., household income, family situation).

Care recipient: Signs of stress in the care recipient are associated with a higher burden of care on the family caregiver (Adelman et al., 2014). Particularly in the case of people living with dementia, the burden of care is largely predicted by characteristics of the disease itself (Kim et al., 2012). Above all, the presence of challenging behaviors (e.g., hallucinations, depression, irritability, aggressiveness) has been shown to be the strongest predictor of family caregiver burden for various diseases (e.g., dementia: Allegri et al., 2006; traumatic brain injury: Ergh et al., 2002; Parkinson's disease: Martinez-Martin et al., 2015). Moreover, strong impairment in terms of mobility and in carrying out tasks of daily living (e.g., washing, getting dressed) predict caregiving burden to a greater extent than does the level of cognitive impairment per se (e.g., measured according to the severity of disease) (Brodaty et al., 2014), although these two aspects are closely related.

Family caregivers: Adelman et al. (2014) summarized characteristics of family caregivers that are associated with a higher burden of care. These include unchangeable sociodemographic factors as well as changeable behaviors that arise in response to the care situation. With regard to sociodemographic factors, it is apparent that female caregivers as well as persons with low educational attainment are particularly burdened (Adelman et al., 2014). Family caregivers who indicate that they had no choice but to take on the caregiving also report a higher burden (Adelman et al., 2014). With regard to behaviors, above all, social isolation and reduced activity levels constitute both risk factors and consequences of increased caregiver burden (Adelman et al., 2014).

Living situation: In terms of the living situation, Adelman et al. (2014) summarized that family caregivers who live with the care recipient are particularly burdened. Moreover, an additional financial strain due to the care situation exerts a negative influence on caregivers' burden (Lai, 2012). In addition, family conflicts surrounding the care situation, as well as a lack of appreciation for the caregiver's work, are especially burdensome (Etters et al., 2008).



Construction of the RESQ-CARE questionnaire

RESQ-CARE is based on a weighing scale model, in which resilience factors and stress factors are balanced against each other.



■ Theoretical foundations of the questionnaire construction

The RESQ-CARE questionnaire is based on a weighing scale model, in which caregivers' resilience factors and stress factors are balanced against each other. In addition to a general scale capturing sociodemographic information, the questionnaire consists of four scales, two depicting resilience factors ('My strength-givers') and two depicting stress factors ('My strength-sappers'; Figure 1). On the one hand, based on the scores on the individual scales, specific topics for counseling family caregivers can be identified (i.e., Where do the caregiver's strengths/weaknesses lie?). On the other hand, a general evaluation of the caregiving burden can be made in order to quickly identify caregivers who are at particular risk (i.e., Are resilience and stress factors evenly balanced?).

The questionnaire was designed based on a literature review which considered the existing questionnaires on stress and resilience in family caregivers.

Figure 1: Constructs and dimensions underlying the RESQ-CARE scales

	Dimension	Scale
Resilience factors	Psychological dimension of resilience (intra- and interpersonal)	1. My inner attitude
	Social dimension of resilience	2. My sources of energy
Stress factors	Interpersonal dimension of stress factors	3. Difficulties in managing the person I care for
	Intrapersonal dimension of stress factors	4. General challenges

■ Construction of the general scale on sociodemographic characteristics

This scale predominantly assesses unchangeable sociodemographic characteristics of both the family caregiver and the person in need of care. It primarily serves to provide an initial overview of the respondent and his/her living situation. At the same time, it also gives a rough orientation with respect to known risk groups of family caregivers. For instance, studies have indicated that the following factors can be accompanied by a higher caregiving burden (Adelman et al., 2014):

- Female gender

- Low educational attainment
- Co-residence with the care recipient
- High number of hours spent on caregiving per week (> 21 hours per week may indicate increased caregiving burden)

If these four factors occur together in a family caregiver, particular attention should be paid to the questionnaire responses. For instance, if a respondent scores just below the cut-off on a scale, a personal discussion should still be undertaken, in which the respondent is asked specifically if he/she requires counseling, and this should then be offered accordingly.

■ Construction of the resilience scales

The two resilience scales were constructed according to a biopsychosocial approach in line with the classification of resilience factors by Dias et al. (2015) and Joling et al. (2017). The first scale ('My inner attitude') depicts the psychological dimension of resilience and asks about intra- and interpersonal resilience factors. Intrapersonal factors are those relating to the person him/herself (e.g., self-efficacy) while interpersonal factors reflect the relationship with the care recipient (e.g., relationship quality). The second scale ('My sources of energy') primarily captures the social dimension of resilience, i.e., the relationship with other people and one's environment (e.g., social support). As there was no existing questionnaire specifically capturing resilience in family caregivers, the items of this scale were derived from the findings from resilience research in general and from findings on resilience in family caregivers (see tables 1 and 2).

Resilience scale: My inner attitude

The resilience scale 'My inner attitude' depicts the psychological dimension of resilience and primarily asks about intrapersonal resilience factors relating to one's attitude to caregiving and to oneself. Specifically, the items of this scale assess self-efficacy, positive effects of caregiving, the ability to recover from stress, and the level of knowledge about the care recipient's illness.

The construct of self-efficacy, which is seen as a positive resilience factor (Zauszniewski et al., 2015), is depicted by two items. Self-efficacy refers to a person's evaluation of his/her ability to master difficult situations (Bandura, 1977). A high degree of self-efficacy has been related to a lower burden of caregiving (Gallagher et al., 2011). The item 'I am able to rely on my abilities in difficult situations' (item 5) thus reflects self-efficacy. Moreover, the RESQ-CARE questionnaire asks whether the individual voluntarily and deliberately chose to take on the role of being a caregiver (item 1). The rationale behind this item is that the feeling of being trapped in the role, without the possibility for self-determination, is a significant predictor of caregiving burden (Aneshensel et al., 1993; Campbell et al., 2008).

In view of increasing findings that the caregiving situation can also foster growth and maturation (Tarlow et al., 2004), an item on potential positive effects was added (item 2). It is assumed that these positive effects can buffer the negative effects of the caregiving situation. Joling et al. (2017) also define positive caregiving experiences as an important component of resilience in family caregivers. Additionally, the item captures interpersonal resilience factors. In this regard, a good relationship is seen as a protective resilience factor and is associated with a lower caregiver burden (Joling et al., 2017; Quinn et al., 2009) or may even buffer the negative effects of care-related stressors (Lawrence et al., 1998).

The resilience scale 'My inner attitude' depicts the psychological dimension of resilience.

Item 3, which refers to recovery from stress, was taken from the Brief Resilience Scale (Smith et al., 2008), given that a quick recovery from stress is seen as a positive resilience factor. Ultimately, stress is not harmful to health per se; rather, only chronic stress and a lack of ability to bounce back following stressful events are linked to health-damaging effects (McEwen, 1998).

Moreover, item 4 asks about the respondent's level of knowledge about the care recipient's illness. This item additionally covers the caregiver's feelings of competence, as this has emerged as an important resilience factor (Zauszniewski et al., 2015).

Table 1: Overview of constructs underlying items of the scale 'My inner attitude'

No.	Item	Construct	Source
1	I voluntarily and deliberately chose to take on the role of being a caregiver. For example, if the person I care for had other support options, I would still have chosen to take on this role.	Self-efficacy	In line with Campbell et al. (2008)
2	Through the demands of caregiving, I am discovering new, positive sides of myself, of the person I care for, and/or of our relationship with each other.	Growth/ maturation	In line with Tarlow et al. (2004)
3	I recover quickly from stress.	Resilience	In line with Smith et al. (2008)
4	I feel competent in the care I provide. For example, I have gathered information about the condition of the person I care for and support services available to them.	Knowledge about the illness, feeling of competence	In line with Beinart et al. (2012), Zauszniewski et al. (2015)
5	I am able to rely on my abilities in difficult situations.	Self-efficacy	Short Scale for Measuring Self-Efficacy Beliefs (Beierlein et al., 2012)

Resilience scale: My sources of energy

The resilience scale 'My sources of energy' depicts the social dimension of resilience and mainly asks about the presence of social support and about positive recreational activities.

Social contact has been associated with health-conducive effects (Umberson & Montez, 2010). However, both the quantity and in particular the quality of social contacts are important here. In this context, social support is especially relevant. According to the popular stress-buffering hypothesis, social support can buffer the negative effects of stress on health (Cohen & Wills, 1985). In line with this, it is also reported that social support is associated with lower stress in family caregivers (Adelman et al., 2014). Thus, social support can be viewed as an important resilience factor. In the RESQ-CARE questionnaire, social support is captured by three items (items 7 to 9), which address the availability of social contact in general (item 9) and specifically ask about support in caregiving tasks (item 7). Item 8 asks whether the respondent is appreciated by others for the care-related achievements, based on the finding that in addition to providing active support, appreciative and supportive feedback from other family members regarding one's care-related achievements is associated with a lower burden in family caregivers (Li & Sprague, 2002).

The items on social support are complemented by items from the area of self-care and preventing depression. Compared to non-caregivers, family caregivers are exposed to a greater risk of developing depressive disorders (Pinquart & Sörensen, 2003). Therefore, items 6 and 10 target the prevention of depressive disorders. The main symptoms of a depressive episode include a loss of pleasure or joy and a decline in positive activities. Therefore, respondents are asked whether they experience feelings of joy and whether they pursue positive activities in everyday life.

The resilience scale 'My sources of energy' depicts the social dimension of resilience.

Table 2: Overview of constructs underlying items of the scale 'My sources of energy'

No.	Item	Construct	Source
6	Despite the increased demands, I manage to pursue my own interests (such as hobbies, sport).	Self-care/depression prevention	In line with the Beck Depression Inventory (Hautzinger et al., 2009)
7	I involve other people in the care I provide (e.g., family members, friends, community support services, or private support services).	Social support	In line with the stress-buffering hypothesis of Cohen and Wills (1985)
8	I receive positive feedback for the care I provide my care recipient (e.g., from the person I care for, a family member, friend, or healthcare professional).	Social support	In line with Li and Sprague (2002)
9	I have people I can always rely on.	Social support	Berlin Social Support Scales (Schulz & Schwarter, 2003)
10	In my day-to-day life, I experience feelings of joy.	Self-care/depression prevention	In line with the Beck Depression Inventory (Hautzinger et al., 2009; Schulz & Schwarter, 2003)

■ Construction of the stress scales

The two stress scales depict on the one hand interpersonal factors that are primarily attributable to the care recipient's severity of illness, and on the other hand intrapersonal factors that can mainly be ascribed to the changes in the caregiver's living situation due to the care responsibilities.

Stress scale: Difficulties in managing the person I care for

The stress scale 'Difficulties in managing the person I care for' depicts the interpersonal dimension of stress factors.

This scale primarily asks about the presence of behavioral problems as well as impairments in activities of daily living. It not only asks about the mere presence of these symptoms but also explores the effects on the family caregiver. Item 12 asks about a series of behavioral problems which were taken from the Neuropsychiatric Inventory (NPI; Cummings et al., 1994) and have been related to burden in family caregivers in numerous studies (Martinez-Martin et al., 2015; Terum et al., 2017). Besides behavioral problems, impairments in activities of daily living are likewise associated with a higher burden of care (item 11). If these impairments are so strong that the family caregiver is unable to leave the care recipient alone, the stress experience is especially high (item 13). In the context of dementia, this might take the form of an increased tendency to wander, which has been linked to a particularly high caregiver burden in several individual studies (Miyamoto et al., 2002).

Family caregivers can also become stressed if they have the impression that the care recipient has changed (item 14). For instance, in the Caregiver Strain Index (Robinson, 1983), personality changes in the care recipient are related to a feeling of upset in the family caregiver. These personality changes can be attributed to cognitive impairments or to adverse behavioral changes. It has been described that the burden on family caregivers is associated with the degree of cognitive impairment (Bruce et al., 2008). However, behavioral changes such as increased aggressiveness or irritability are also linked to a greater burden (Matsumoto et al., 2007).

Additionally, the scale asks about the frequency of conflicts with the care recipient (item 15), as this predicts a higher burden of care (Pinto et al., 2016). Indirectly, this aspect also addresses impacts on the quality of the relationship with the care recipient, as a good relationship is seen as a protective resilience factor and is associated with a lower burden of care (Joling et al., 2017; Quinn et al., 2009).

Table 3: Overview of concepts underlying items from the scale 'Difficulties in managing the person I care for'

No.	Item	Construct	Source
11	The person I care for has physical limitations and needs assistance with activities of daily living which is difficult for me to provide, such as getting dressed, washing, mobility, eating.	Impairments in activities of daily living	In line with Adelman et al., 2014
12	The person I care for shows behaviors which are challenging for me to cope with (e.g., care recipient does not want support, shows aggressive behavior, has difficulty sleeping, and/or shows a lack of interest in most things).	Behavioral problems	Neuropsychiatric Inventory (Cummings et al., 1994)
13	I cannot leave the person I care for alone for an hour.		In line with Miyamoto et al., 2002
14	The person I care for has changed for the worse due to their condition (e.g., is more irritable, more negative, less compassionate, has mentally declined).	Personality changes	In line with the Caregiver Strain Index (Robinson, 1983)
15	I experience a lot of conflict and arguments with the person I care for.	Change in the relationship	In line with Pinto et al., 2016

Stress scale: General challenges

This stress scale asks about additional stressors in the everyday life of the family caregiver, which are not specific to the care situation. Besides characteristics of the care recipient and the caregiver, a third primary source of stress is general challenges. Therefore, item 16 asks initially about additional burdens in general. These can pertain to one's own health, which is covered in more detail in item 17, or role conflicts, especially the reconcilability of care and one's work (Gordon et al., 2012). It is important to keep in mind that health problems can be both a consequence of the care burden and a risk factor for a higher care burden (Chang et al., 2010; Richardson et al., 2013). A low income is also seen as a predictor of a higher care-related burden (item 18), and financial worries are therefore addressed in almost all commonly used questionnaires on caregiving burden (e.g., Zarit Burden Interview, Zarit et al. (1985); Caregiver Strain Index, Robinson (1983)). The Berlin Inventory of Caregivers' Burden with Dementia Patients (BIZA-D; Zank et al., 2006) contains a separate 'Finances' scale.

Family caregivers often neglect their own health (e.g., failing to attend medical appointments), are particularly vulnerable, and show a higher mortality (Schulz & Beach, 1999). It can be assumed that this neglect of one's own health is due to the large amount of time taken up by caregiving tasks. Therefore, finally, item 19 asks indirectly about role conflicts, as these can represent a particular vulnerability to additional care-related burden. As many family caregivers either restrict their leisure time in order to fulfill the care requirements or reduce their working hours, item 20 asks to what extent the respondent feels that he/she is unable to keep up with the demands of everyday life, which can be seen as a further indicator of possible role conflicts.

The stress scale 'General challenges' depicts the intra-personal dimension of stress factors.

Table 4: Overview of constructs underlying the items of the scale 'General challenges'

No.	Item	Construct	Source
16	I am burdened by other stressors in everyday life outside of my caregiving role (e.g., my own health and well-being, worries about other family members, finding balance with caregiving-family-work).	Stressors of general living situation	In line with the Caregiver Strain Index (Robinson, 1983)
17	I experience physical health challenges on a daily basis (e.g., pain, shortness of breath, unwanted weight change, heart palpitations, dizziness, or problems with my muscles, joints, or bones).	State of health	In line with Richardson et al. (2013) and Gräßel (1998)
18	I am worried about my financial situation.	Financial worries	In line with the Caregiver Strain Index (Robinson, 1983), Zarit Burden Interview (Zarit et al., 1985), Berlin Inventory of Caregivers' Burden with Dementia Patients (Zank et al., 2006)
19	I neglect my own health and well-being (e.g., missing medical appointments, experiencing a lack of sleep, eating poorly).	State of health	In line with Schulz and Beach (1999)
20	I feel like I cannot keep up with the many demands in my everyday life.	Role conflicts	In line with the Caregiver Strain Index (Robinson, 1983) and the In-Home Care Scale (Gräßel, 2001)

■ Additional Module on Dementia

Every three seconds, somebody in the world develops dementia (Alzheimer's Disease International, 2020). Around 55 million people worldwide are affected by dementia (Alzheimer's Disease International, 2020), and approximately 1.8 million in Germany (Deutsche Alzheimer Gesellschaft, 2022). The majority of people living with dementia are cared for by family members in the home (Tremont, 2011). These family caregivers are often described as 'invisible second patients' (Brodaty & Donkin, 2009).

Due to an increased level of stress, family caregivers of people living with dementia are at particular risk of developing physical and/or mental illness themselves (Wuttke-Linnemann et al., 2019). The risk of developing depression is especially high – according to estimates, the proportion of depressive disorders in family caregivers of people living with dementia lies between 15 and 32% (Cuijpers, 2005), i.e., between one in three and one in seven family caregivers are affected by depression.

Research has indicated that the disease-related characteristics of the person living with dementia account for the greatest share of the care burden. Kim et al. (2012) estimate that 16% of the burden of family caregivers can be attributed to the care recipient's dementia symptoms. In this regard, a multitude of studies suggest that the presence of behavioral problems predicts a higher burden for the caregiver. In a review, Terum et al. (2017) found that in particular, irritability, agitation, sleep disturbances, anxiety, apathy and hallucinations in the person living with dementia predict higher burden in family caregivers.

For these reasons, RESQ-CARE includes an additional module for family caregivers of people living with dementia, the RESQ-CARE-DEM questionnaire. The difference to the RESQ-CARE questionnaire lies in the stress scale, which specifically addresses difficulties in managing the person living with dementia.

Stress scale: Difficulties in managing the person living with dementia

This scale primarily asks about behavioral problems of the person living with dementia and about how the family caregiver deals with these problems. Item 12 covers a series of behavioral problems taken from the Neuropsychiatric Inventory (NPI; Cummings et al., 1994), which have been related to burden in family caregivers within numerous studies (Terum et al., 2017). Among other things, in people living with dementia, the tendency to wander is associated with a particularly high caregiving burden (Miyamoto et al., 2002), as people living with dementia who are mobile can barely be left alone by their family caregivers. Besides behavioral problems, impairments in activities of daily living are also linked to a higher caregiving burden (item 11). Additionally, due to particular behavioral problems (e.g., disinhibition), some family caregivers experience feelings of embarrassment, which can in turn trigger and reinforce social withdrawal tendencies. Martin et al. (2006) found that feelings of shame in family caregivers (e.g., as they feel unable to fulfill others' expectations) are linked to higher depression scores. For this reason, item 13 asks about care-related shame. The shifting roles also pose a burden for family caregivers (item 14). Shortly after the onset of illness, the majority of caregivers report that a previously equal relationship is no longer equal (Eloniemi-Sulkava et al., 2002). As caregivers often have to assume responsibility for areas of life that care recipients used to manage themselves, a feeling of being overwhelmed can bring further burden. Moreover, the scale asks about the quality of the relationship with the person living with dementia (item 15), as conflicts in the relationship are associated with a higher caregiving burden (Tough et al., 2017)

For family caregivers of people living with dementia, the RESQ-CARE-DEM is available.

In contrast to the RESQ-CARE, the RESQ-CARE-DEM asks about dementia-specific factors within the stress scale 'Difficulties in managing the person living with dementia'.

Table 5: Overview of constructs underlying items of the scale 'Difficulties in managing the person living with dementia'

No.	Item	Construct	Source
11	The person living with dementia has physical limitations and needs assistance with activities of daily living which is difficult for me to provide, such as getting dressed, washing, mobility, eating.	Impairments in activities of daily living	In line with Adelman et al., 2014
12	The person living with dementia shows behaviors which are challenging for me to cope with (e.g., hallucinations, aggressive behavior, tendency to wander, (nighttime) restlessness, lack of interest).	Behavioral and psychological symptoms of dementia	Neuropsychiatric Inventory (Cummings et al., 1994)
13	I find it difficult to be with the person living with dementia in public (fear of embarrassing situations, lack of understanding, loss of control).	Care-related shame	In line with Martin et al. (2006)
14	It really bothers me that the person living with dementia has changed and I therefore have to take on more responsibility.	Change in the relationship	In line with the Caregiver Strain Index (Robinson, 1983)
15	I experience a lot of conflict and arguments with the person living with dementia.	Relationship quality	In line with Tough et al. (2017)

Family caregivers of people living with dementia should be given the RESQ-CARE-DEM questionnaire. An evaluation version and an evaluation sheet are also available for this questionnaire (Appendix 4-6).



Using the questionnaire

■ Aim of the questionnaire

The aim of the RESQ-CARE questionnaire is to identify resilience factors and stress factors in family caregivers. The use of the questionnaire should on the one hand help counselors to assess the need for counseling (i.e., On which themes is counseling required?) and on the other hand support the assessment of the overall burden on the family caregiver (i.e., How critical is the care situation for the family caregiver?).

In the context of professional counseling for care-related matters, the completed questionnaire can thus serve to identify counseling themes in order to foster resilience and reduce burden. Moreover, the questionnaire enables resilience factors and stress factors to be balanced against each other, allowing conclusions to be drawn about the ratio of resilience factors to stress factors, e.g., whether the weighing scales are balanced. In this way, family caregivers who are at risk or especially vulnerable can be identified.

The questionnaire is targeted at family caregivers and is not suitable for use with professional caregivers.

■ Construction of the questionnaire

The questionnaire is composed of four scales, two assessing resilience factors and two assessing stress factors. The two resilience scales are described as strength-givers and the two stress scales are described as strength-sappers.

Figure 2: Presentation of the four scales of the RESQ-CARE questionnaire

		Dimension	Scale
Resilience factors	My strength-givers	Psychological dimension of resilience (intra- and interpersonal)	1. My inner attitude
		Social dimension of resilience	2. My sources of energy
Stress factors	My strength-sappers	Interpersonal dimension of stress factors	3. Difficulties in managing the person I care for
		Intrapersonal dimension of stress factors	4. General challenges

The tool is conceived as a self-report questionnaire and should be filled out by family caregivers prior to counseling.

■ Filling out the questionnaire

The questionnaire is designed as a self-report form and should be given to the family caregiver to fill out before a counseling session. It takes approximately 15 minutes to complete.

The following personal instructions may be given:

‘To get a proper overview of your care situation, of your strengths and your burdens, I would like to ask you to fill out this questionnaire. Please refer to the last four weeks when answering. This will give me a better overview of your care situation and I’ll be able to tailor my advice your needs.’

Additionally, the questionnaire contains the following instructions:

Dear family caregiver,

Caring for somebody in need changes one’s everyday life. Family caregivers deal with this new situation in different ways. While there are some who recover from stress quickly, the majority of family caregivers are at risk of developing physical/and or mental health problems themselves due to the additional stress. This risk depends on various factors, but especially on one’s own resilience, social support, and care-related burden.

The aim of this questionnaire is to find out how your current situation is influenced by these positive or negative factors. Based on your answers, we would like to be able to offer optimal advice/support that is tailored to your needs. For this purpose, it is important that you answer the questions based on your current situation. Please look back over the last four weeks when responding. Your answers will be treated confidentially.

■ Evaluation

The questionnaire can be evaluated in ten minutes. First of all, a sum score for each scale is calculated. The answers are scored as follows:

Table 6: Scoring system for the RESQ-CARE questionnaire

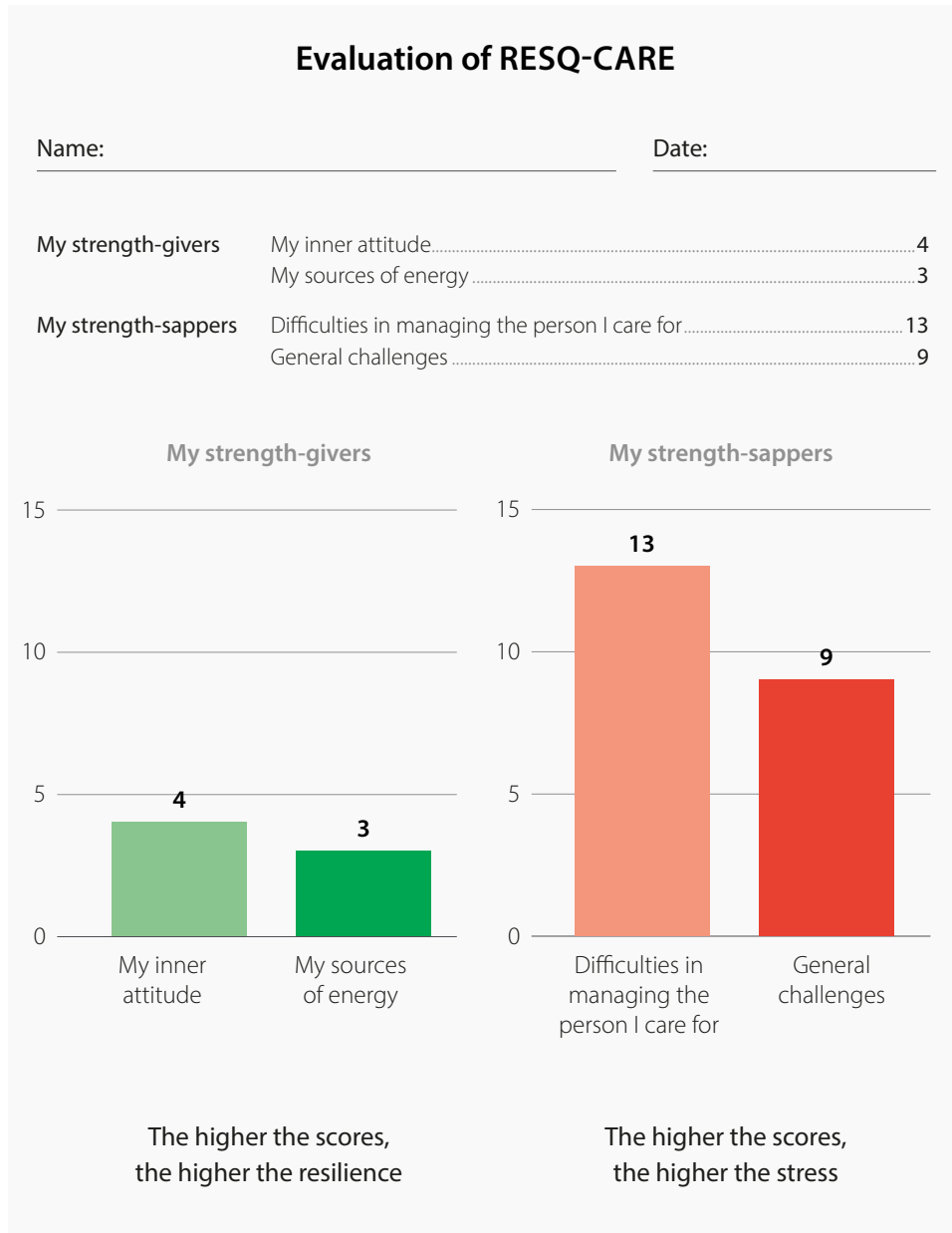
Strongly agree	Agree	Disagree	Strongly disagree
3	2	1	0

For each scale, the sum score can range between 0 and 15, with high scores on the resilience scales indicating high resilience and high scores on the stress scales indicating high stress.

The scores on the four scales are not added together. There is no total score for the questionnaire.

To facilitate the evaluation and subsequent graphical display of the results, the Excel file in Appendix 3 can be used. First, the individual scores for each question are entered into the spreadsheet 'The raw scores'. A visual display of the results then appears automatically in the spreadsheet 'The evaluation' (Figure 3).

Figure 3: Visual display of results of the RESQ-CARE questionnaire



High scores on the resilience scales indicate high resilience and high scores on the stress scales indicate high stress.

■ Interpreting the results

Results of the individual scales

To plan the counseling based on the results of the individual scales, no total score on the questionnaire is calculated. Instead, the sociodemographic basis score as well as the four resilience and stress scales are interpreted separately.

Rating scheme

Studies have indicated that the following factors can be associated with a higher burden of care (Adelman et al., 2014): female gender, low educational level, co-residence with the care recipient, higher number of hours spent caring per week.

Sociodemographic basis scale

	No	Yes
Female gender	<input type="radio"/>	<input type="radio"/>
Low educational attainment	<input type="radio"/>	<input type="radio"/>
Co-residence with person in need of care	<input type="radio"/>	<input type="radio"/>
Over 21 hours per week spent on caregiving	<input type="radio"/>	<input type="radio"/>
Does the number of YES responses amount to 4?	<input type="radio"/>	<input type="radio"/>

If all four criteria are fulfilled, the family caregiver belongs to a particularly at-risk group.

If a person scores just below the cut-off on one of the subsequent scales (i.e., at least two questions are answered with Strongly disagree or Disagree on the resilience scales and/or two questions are answered with Strongly agree or Agree on the stress scales), a personal conversation should nevertheless be conducted, in which the individual is specifically asked about the need for counseling and corresponding counseling is offered.

Resilience and stress scales

Scale	Rule	Rule met?
1. My inner attitude	If Strongly disagree or Disagree to at least 2 questions	<input type="radio"/> Yes <input type="radio"/> No
2. My sources of energy	If Strongly disagree or Disagree to at least 2 questions	<input type="radio"/> Yes <input type="radio"/> No
3. Difficulties in managing the person I care for	If Strongly agree or Agree to at least 2 questions	<input type="radio"/> Yes <input type="radio"/> No
4. General challenges	If Strongly agree or Agree to at least 2 questions	<input type="radio"/> Yes <input type="radio"/> No

The sociodemographic basis scale and the four resilience and stress scales are all interpreted separately.

Identifying counseling themes

If the cut-off score on a scale is reached (i.e., at least 2 questions are answered with Strongly disagree or Disagree on the resilience scales and/or at least 2 questions are answered with Strongly agree or Agree on the stress scales), the counseling themes relating to the scale on which this score was exceeded should be discussed.

Example: If the cut-off is reached on all four scales, all themes would lend themselves to the counseling.

If the cut-off is reached on only one scale (e.g., My sources of energy), the counseling can delve more deeply into the themes suggested for this area (possibilities for relaxation, self-help groups, self-care).

If all four of the questions on the Sociodemographic Basis Scale are answered in the affirmative, then the respondent is seen as belonging to a particularly at-risk group. In this case, counseling themes should still be selected, even if only one question was answered with Strongly disagree or Disagree (resilience scales) or with Strongly agree or Agree (stress scales) and the cut-off thus narrowly missed.

Interpretation scheme of the RESQ-CARE questionnaire

Scale	Rule	Possible counseling themes
1. My inner attitude	If Strongly disagree or Disagree to at least 2 questions	<ul style="list-style-type: none"> · Self-care · Stress management · Problem-solving training
2. My sources of energy	If Strongly disagree or Disagree to at least 2 questions	<ul style="list-style-type: none"> · Possibilities to ease the burden (e.g., day care, in-home care) · Self-help groups · Self-care
3. Difficulties in managing the person I care for	If Strongly agree or Agree to at least 2 questions	<ul style="list-style-type: none"> · Psychoeducation · Psychoeducation on challenging behavior, referral to a specialist physician for care recipient · Self-help groups
4. General challenges	If Strongly agree or Agree to at least 2 questions	<ul style="list-style-type: none"> · Aspects of social welfare law (possibly debt counseling) · Medical/psychiatric/psychotherapeutic assessment/diagnosis of the family caregiver

Cut-off rule:
Strongly disagree or Disagree to at least 2 questions on the resilience scales or Strongly agree or Agree to at least 2 questions on the stress scales?
→ Select and offer corresponding counseling themes.

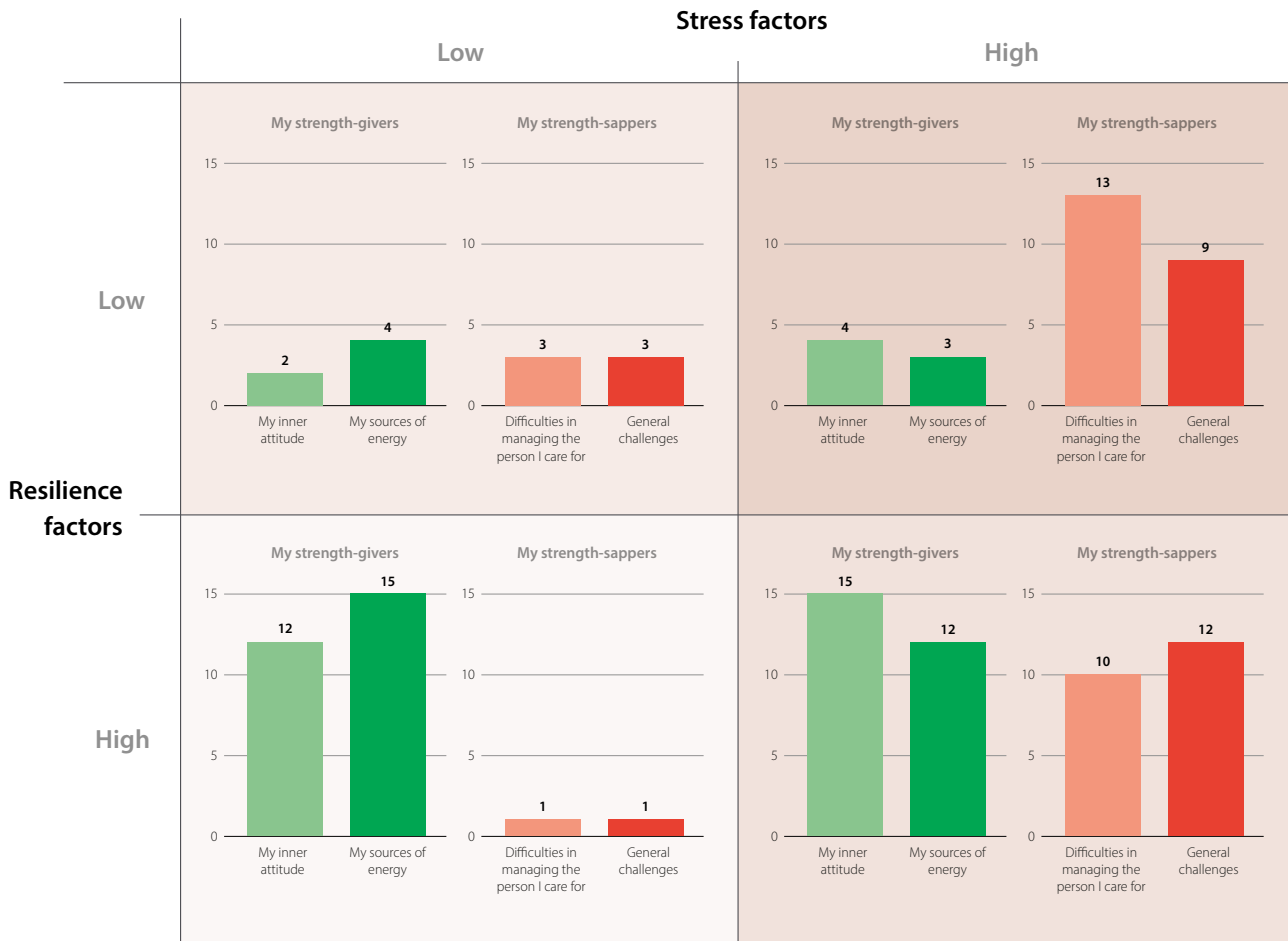
Ratio of resilience factors to stress factors

To enable conclusions to be drawn about the ratio of resilience factors to stress factors, the mean scores on the two resilience scales are compared with the mean scores on the two stress scales. This process enables especially vulnerable caregivers, i.e., those at risk, to be identified.

The following four evaluation scenarios are possible. Particular attention should be paid to family caregivers who show high stress factors and simultaneously low resilience factors (top right). This group is especially at risk. There is less need for intervention for caregivers who show high resilience factors and low stress factors (bottom left). For the other two groups, the resilience and stress factors are currently balancing each other out, but at the same time, resilience should be fostered (top left) and burden reduced (bottom right) for these groups.

Family caregivers with low resilience scores and simultaneously high stress scores are especially at risk.

Figure 4: Evaluation scenarios RESQ-CARE



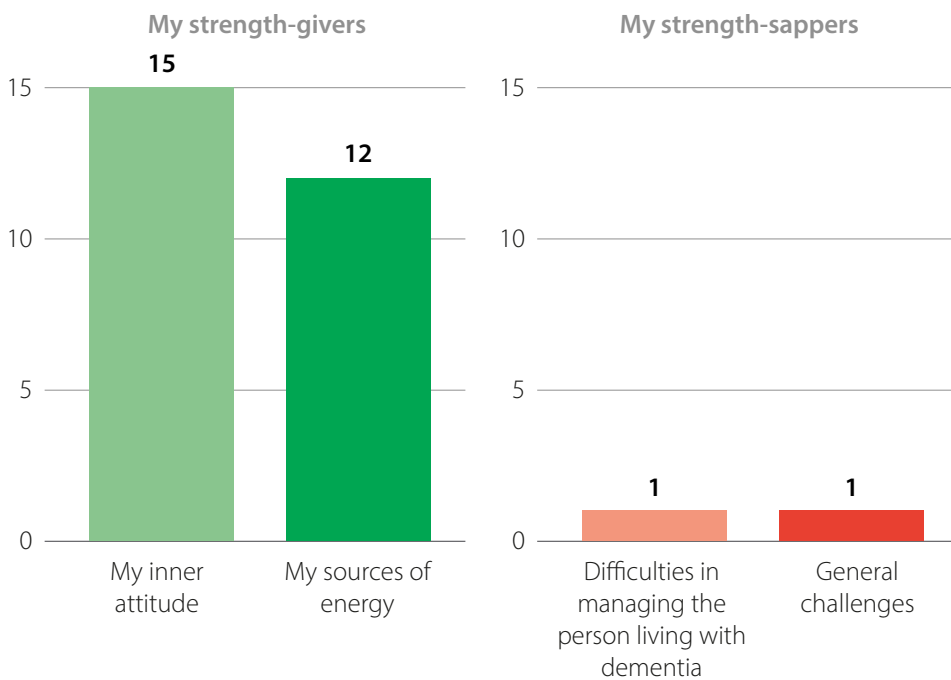
Evaluation example 1: High resilience, low stress

Case example: The K family.

Mr. K (76) has been caring for his wife living with dementia for the last year. He has three children who all live nearby and regularly come to visit. Mr. K is himself actively involved in many clubs and associations and has communicated openly about his wife's illness. If Mrs. K wanders around the village, as often happens, the neighbors are now aware of the situation and help her to find her way back home. Mr. K has the support of a home care service, which regularly comes to wash Mrs. K, and Mrs. K gets along well with the professional carer. Mr. K also appreciates the professional carer, who has explained a lot to him about managing people living with dementia. In addition, Mrs. K goes to a day care facility several times a week. During this time, Mr. K pursues his hobbies and above all spends time in the garden. If things were to become more difficult, Mr. K can envisage enabling the situation at home to continue by bringing in additional home carers. He is financially well off, so does not have to worry about funding the care.

Interpretation and need for counseling

In the RESQ-CARE-DEM questionnaire, Mr. K has high scores on the two resilience scales (in particular, he scores the maximum 15 points on the scale 'My sources of energy') and low scores on the two stress scales.



With high resilience and low stress, there is currently no need for counseling.

It is clear from the description that Mr. K's strengths lie especially in the area of social resilience factors. Likewise, it is particularly positive that his general living situation does not entail any particular burdens. Mr. K already has a plan of action should his wife's condition deteriorate, and is informed about available support offers.

There is currently no need for counseling.

Evaluation example 2: High resilience, high stress

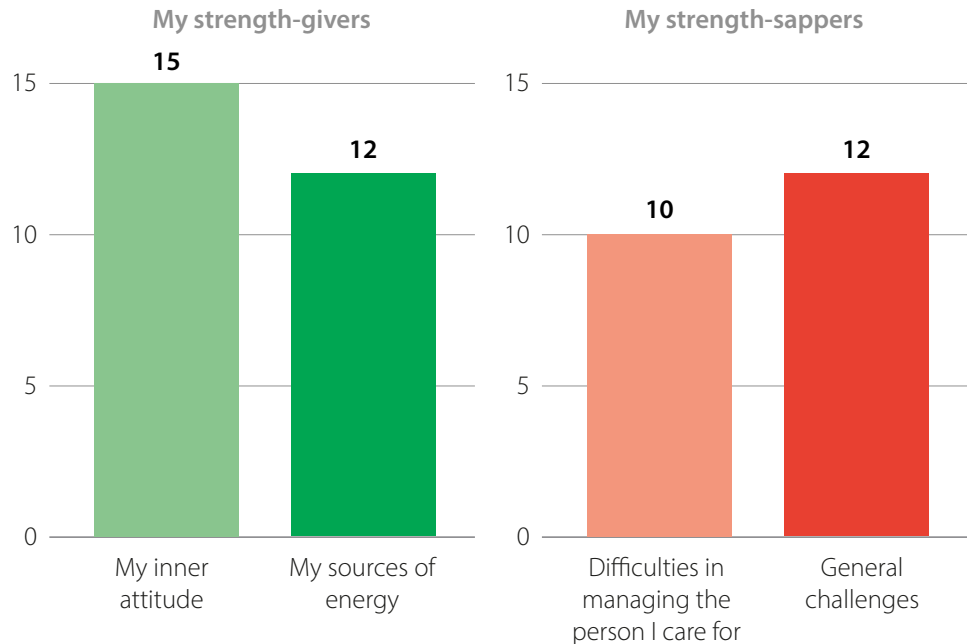
Case example: Mrs. S and her mother Mrs. L.

Mrs. S (54) has been caring for her mother, who has Parkinson’s disease and has also suffered two severe strokes, for around two years. Mrs. S is a salaried employee and works part-time. She has three children, the two eldest of whom have already moved out. She lives with her husband. After her mother’s first stroke and the consequent limits to her mobility, Mrs. S brought in support and delegated many of the caregiving tasks to a home care service. She says she would rather share the good times with her mother than discussing matters like washing and getting dressed. On the whole, she has always had a good and appreciative relationship with her mother and she finds it important to now be able to give something back. In addition, her mother attends a day care center for senior citizens three times a week. In the last few weeks, her mother’s state of health has deteriorated. Mrs. S has often had to take time off work in order to be with her mother more. This has led to additional stress because she can’t carry out her job like usual and the work is starting to pile up. Her husband is also often annoyed because Mrs. S is at home so little. The question has arisen of whether it is necessary for her mother to move into a residential home or whether the current home-based care can be maintained.

Interpretation and need for counseling

Mrs. S shows high scores on the two resilience scales; in particular, she scores the maximum 15 points on the scale ‘My inner attitude’. At the same time, she also has high scores on the two stress scales, and especially on the scale ‘General challenges’.

With high resilience and high stress, caregivers should first be praised for their many resilience factors and should be counseled on reducing burden.



In the counseling, it should first be reported back to Mrs. S that she has a particular number of strengths and a multitude of resilience factors. These resilience factors constitute a good starting point from which to better buffer against the burdens arising from the care situation. Therefore, the counseling should focus on reducing the general challenges.

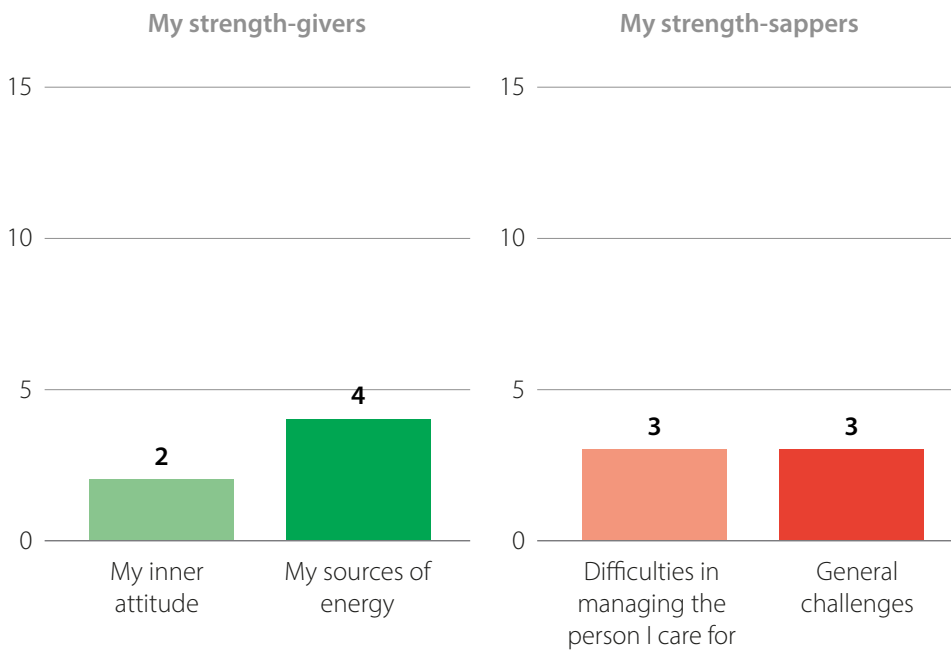
Evaluation example 3: Low resilience, low stress

Case example P family

Mrs. P (74) lives with her husband, who has been diagnosed with cancer, which he has suffered from several times before. They live on and run a small farm. The business has since been passed down to the couple's children but the parents still help out when needed. Mr. P has always taken care of everything, especially the finances. At the moment he is finding this more difficult, but as Mrs. P doesn't have her own bank account and is not aware of all the tasks her husband takes care of, she continues to leave these areas to him. So far, she is not yet experiencing any major limitations due to her husband's illness, but her family doctor has urgently advised her to receive some caregiving counseling.

Interpretation and need for counseling

In the RESQ-CARE questionnaire, Mrs. P has low scores on all scales (answering every question with 1 or 2). Particularly on the scale 'My inner attitude', Mrs. P often didn't know what she should answer. It becomes clear here that she has not yet come to terms with her husband's recurring illness and its consequences. She left the question about financial worries unanswered, because she has never dealt with this area.



With low resilience and low stress, caregivers should receive preventive counseling on fostering resilience.

The counseling for Mrs. P should take a preventive approach, aiming especially to strengthen resilience so that she is capable of action if the burden increases. Therefore, Mrs. P should receive psychoeducational counseling on the illness and above all on the upcoming change in roles. Furthermore, she should already receive information about possibilities for support and about the importance of self-care.

Evaluation example 4: Low resilience, high stress

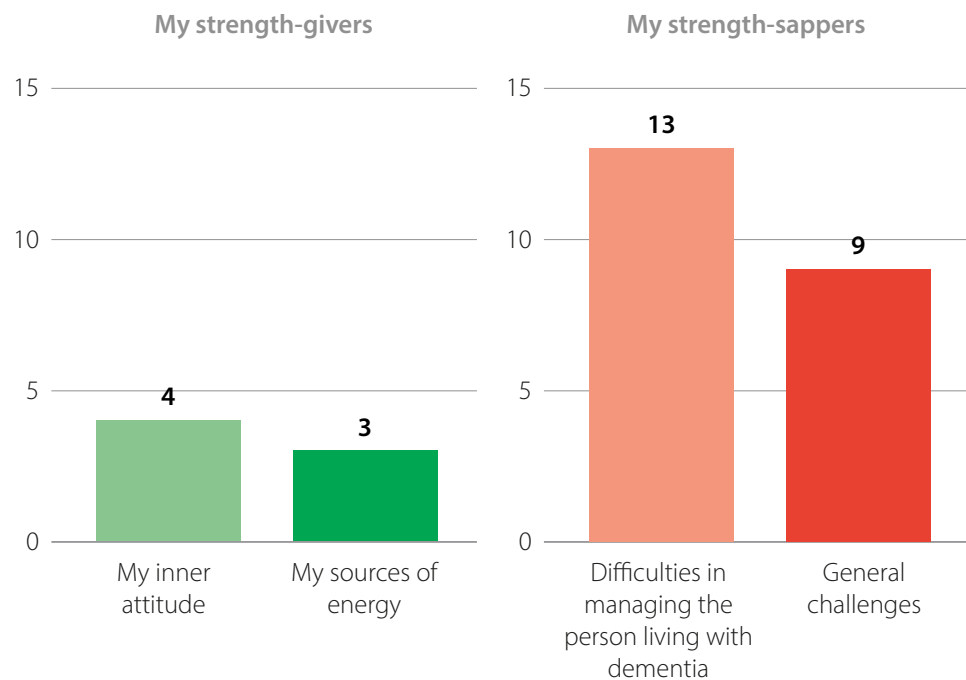
Case example M family

Mrs. M (78) has been caring for her husband with dementia for five years. So far she has not bothered about support possibilities because she has always 'somehow got by'. Also, she has not yet told anybody that her husband is suffering from dementia. For the last few weeks, however, her husband's health has drastically deteriorated. For instance, he is constantly asking the same questions and she can no longer have a conversation with him. At night, her husband is often awake and walking around the house. For several weeks, Mrs. M has not been able to get any restful sleep. She also has to support him with his personal hygiene more, meaning that she already suffers from backache every day. On the whole, she is currently withdrawing even more. She does have children, but she doesn't want to place any additional burden on them.

Interpretation and need for counseling

Mrs. M has very low scores on both resilience scales and high scores on the two stress scales, particularly on the scale assessing behavioral difficulties. But also the questions about one's own health point to a high additional burden. On the questions from the scale 'My sources of energy', she indicates that she is only just noticing that she has actually withdrawn a great deal over the last few years. She has always done everything together with her husband and has never had her own hobbies.

With low resilience and high stress, caregivers should receive detailed counseling on fostering resilience and reducing burden.



Mrs. M is at particular risk and requires urgent counseling in order to reduce burden and foster resilience. In addition to psychoeducational elements on dementia, as well as available support offers, she should above all be advised about activating social support.



Deriving recommendations for action

Based on the results of the questionnaire and the scale scores, the counseling themes can be additionally supplemented by concrete recommendations for action and/or interventions for the family caregiver.

Scale	Possible interventions
1. My inner attitude	Introduce a positivity journal
	Exercises to increase self-esteem (e.g., make a list of positive qualities, values questionnaire, resource journal)
	Relaxation exercises (e.g., progressive muscle relaxation, PMR), mindfulness (e.g., 5-4-3-2-1 exercise)
	Exercises to promote acceptance
	Exercises to deal with self-criticism
2. My sources of energy	Help the caregiver to develop a list of positive activities
	Introduce a weekly schedule under consideration of the weighing scale model
	Foster social contacts (e.g., develop a social network map and use it to promote getting in touch with others)
3. Difficulties in managing the person I care for	Social competence training on managing challenging behavior
	Information and arrangement of offers of help and support
	Draw up a support network (which social contacts are good helpers for comfort and support, for distraction and leisure, for practical help and errands?)
	Exercises to promote acceptance
4. General challenges	Problem-solving training
	Relaxation exercises (e.g., PMR)
	Exercises to promote mindfulness (e.g., 5-4-3-2-1 exercise) and acceptance



Appendix

1. RESQ-CARE questionnaire application version
2. RESQ-CARE questionnaire evaluation version
3. RESQ-CARE evaluation sheet (Excel file)
4. RESQ-CARE-DEM questionnaire application version
5. RESQ-CARE-DEM questionnaire evaluation version
6. RESQ-CARE-DEM evaluation sheet (Excel file)



Date	Code	Counselor
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Resilience and Strain Questionnaire for Caregivers (RESQ-CARE)

Dear family caregiver,

Caring for somebody in need changes one's everyday life. Family caregivers deal with this new situation in different ways. While there are some who recover from stress quickly, the majority of family caregivers are at risk of developing physical and/or mental health problems themselves due to the additional stress. This risk depends on various factors, but especially on one's own resilience, social support, and care-related burden.

The aim of this questionnaire is to find out how your current situation is influenced by these positive or negative factors. Based on your answers, we would like to be able to offer you optimal advice/support that is tailored to your needs. For this purpose, it is important that you answer the questions based on your current situation. Please look back over the last four weeks when responding. Your answers will be treated confidentially.

My personal information

Age	Years	
Gender	<input type="radio"/> Female <input type="radio"/> Male	<input type="radio"/> Other
Relationship to the person I care for (I am the ...)	<input type="radio"/> Spouse <input type="radio"/> Parent	<input type="radio"/> Child <input type="radio"/> Other:
Living situation	<input type="radio"/> Together with the person I care for <input type="radio"/> Alone	<input type="radio"/> With one's own family, partner <input type="radio"/> Other:
Highest educational attainment	<input type="radio"/> Primary school <input type="radio"/> High school <input type="radio"/> University	<input type="radio"/> Postgraduate <input type="radio"/> No qualifications
Occupation	<input type="radio"/> Retired <input type="radio"/> Part-time <input type="radio"/> In training/studying	<input type="radio"/> Unemployed <input type="radio"/> Full-time
Time spent on caregiving	hours/week	

Information on the person I care for

Age	Years	
Gender	<input type="radio"/> Female <input type="radio"/> Male	<input type="radio"/> Other
Illnesses	<input type="radio"/> Stroke <input type="radio"/> Cancer <input type="radio"/> Parkinson's disease	<input type="radio"/> Dementia <input type="radio"/> Other(s):
Living situation	<input type="radio"/> Lives at home	<input type="radio"/> Lives in an institution





My strength-givers

1. My inner attitude

	Strongly agree	Agree	Disagree	Strongly disagree
1. I voluntarily and deliberately chose to take on the role of being a caregiver. For example, if the person I care for had other support options, I would still have chosen to take on this role.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Through the demands of caregiving, I am discovering new, positive sides of myself, of the person I care for, and/or of our relationship with each other.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. I recover quickly from stress.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. I feel competent in the care I provide. For example, I have gathered information about the condition of the person I care for and support services available to them.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. I am able to rely on my abilities in difficult situations.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

2. My sources of energy

	Strongly agree	Agree	Disagree	Strongly disagree
6. Despite the increased demands, I manage to pursue my own interests (such as hobbies, sport).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. I involve other people in the care I provide (e.g., family members, friends, community support services, or private support services).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. I receive positive feedback for the care I provide my care recipient (e.g., from the person I care for, a family member, friend, or healthcare professional).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. I have people I can always rely on.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. In my day-to-day life, I experience feelings of joy.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

My strength-sappers

3. Difficulties in managing the person I care for

	Strongly agree	Agree	Disagree	Strongly disagree
11. The person I care for has physical limitations and needs assistance with activities of daily living which is difficult for me to provide, such as getting dressed, washing, mobility, eating.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. The person I care for shows behaviors which are challenging for me to cope with (e.g., care recipient does not want support, shows aggressive behavior, has difficulty sleeping, and/or shows a lack of interest in most things).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. I cannot leave the person I care for alone for an hour.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>





14. The person I care for has changed for the worse due to their condition (e.g., is more irritable, more negative, less compassionate, has mentally declined).
-
15. I experience a lot of conflict and arguments with the person I care for.
-

4. General challenges

- | | Strongly agree | Agree | Disagree | Strongly disagree |
|--|-----------------------|-----------------------|-----------------------|-----------------------|
| 16. I am burdened by other stressors in everyday life outside of my caregiving role (e.g., my own health and well-being, worries about other family members, finding balance with caregiving-family-work). | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 17. I experience physical health challenges on a daily basis (e.g., pain, shortness of breath, unwanted weight change, heart palpitations, dizziness, or problems with my muscles, joints, or bones). | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 18. I am worried about my financial situation. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 19. I neglect my own health and well-being (e.g., missing medical appointments, experiencing a lack of sleep, eating poorly). | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 20. I feel like I cannot keep up with the many demands in my everyday life. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

I'd like to add the following comments:

Many thanks for filling out the questionnaire!





Date	Code	Counselor
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Resilience and Strain Questionnaire for Caregivers (RESQ-CARE)

– Evaluation –

1. For orientation, evaluate the sociodemographic characteristics of the family caregiver

	No	Yes
Female gender	<input type="radio"/>	<input type="radio"/>
Low educational attainment	<input type="radio"/>	<input type="radio"/>
Co-residence with person in need of care	<input type="radio"/>	<input type="radio"/>
More than 21 hours/week spent on caregiving	<input type="radio"/>	<input type="radio"/>
Does the total of YES answers amount to 4?	<input type="radio"/>	<input type="radio"/>

If all four criteria are present, the family caregiver belongs to a special risk group.

2. Assign the following scores to the answers

Strongly agree	Agree	Disagree	Strongly disagree
3	2	1	0

To do so, you can use the original questionnaire and note the respective scores next to the answers.

3. For each scale, check whether the following rule is fulfilled

Scale	Rule	Rule fulfilled?	
1. My inner attitude	Strongly disagree or Disagree to at least 2 questions	<input type="radio"/> Yes	<input type="radio"/> No
2. My sources of energy	Strongly disagree or Disagree to at least 2 questions	<input type="radio"/> Yes	<input type="radio"/> No
3. Difficulties in managing the person I care for	Strongly agree or Agree to at least 2 questions	<input type="radio"/> Yes	<input type="radio"/> No
4. General challenges	Strongly agree or Agree to at least 2 questions	<input type="radio"/> Yes	<input type="radio"/> No





If, for 3., at least 2 questions on the resilience scales were answered with Strongly disagree or Disagree and/or at least 2 questions on the stress scales were answered with Strongly agree or Agree, the counseling themes corresponding to the scale should be suggested.

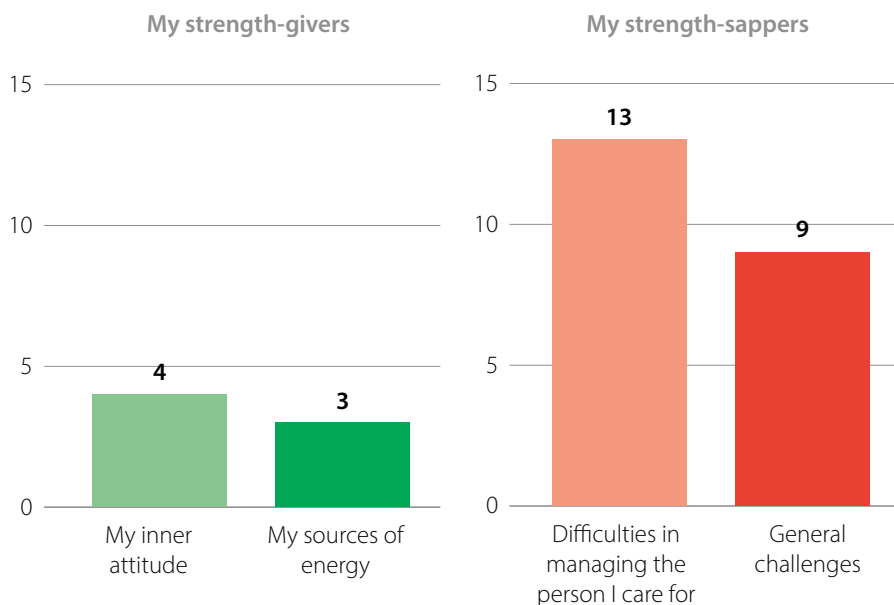
If, for 1., all questions were answered with Yes, counseling should be offered even if the aforementioned cut-off scores were narrowly missed (see manual).

4. Identify the counseling themes

Scale	Counseling themes	Recommendation
1. My inner attitude	Self-care	<input type="radio"/>
	Stress management	<input type="radio"/>
	Problem-solving training	<input type="radio"/>
2. My sources of energy	Possibilities to relieve burden (e.g., day care, in-home care)	<input type="radio"/>
	Self-help groups	<input type="radio"/>
	Self-care	<input type="radio"/>
3. Difficulties in managing the person I care for	Psychoeducation	<input type="radio"/>
	Psychoeducation on challenging behavior	<input type="radio"/>
	Refer person in need of care to specialist physician	<input type="radio"/>
	Self-help groups	<input type="radio"/>
4. General challenges	Aspects of social welfare law (possibly debt counseling)	<input type="radio"/>
	Medical/psychiatric/psychotherapeutic assessment/diagnosis of the family caregiver	<input type="radio"/>

5. Transfer the scores for the individual answers to the Excel sheet to obtain a visual evaluation of the questionnaire

Example of visual evaluation





Resilience and Strain Questionnaire for Caregivers (RESQ-CARE) – Evaluation –

Instructions for filling out RESQ-CARE:

Please enter here the numerical value that the family caregiver gave for each question.

The answers are scored as follows:

Strongly agree 3 Agree 2 Disagree 1 Strongly disagree 0

You can then see a visual display of the results in the next spreadsheet, „The evaluation“.

My strength-givers

1. My inner attitude

1. I voluntarily and deliberately chose to take on the role of being a caregiver.	
2. Through the demands of caregiving, I am discovering new, positive sides of myself, of the person I care for, and/or of our relationship with each other.	
3. I recover quickly from stress.	
4. I feel competent in the care I provide. For example, I have gathered information about the condition of the person I care for and support services available to them.	
5. I am able to rely on my abilities in difficult situations.	

Total

2. My sources of energy

6. Despite the increased demands, I manage to pursue my own interests.	
7. I involve other people in the care I provide.	
8. I receive positive feedback for the care I provide my care recipient.	
9. I have people I can always rely on.	
10. In my day-to-day life, I experience feelings of joy.	

Total

My strength-sappers

3. Difficulties in managing the person I care for

11. The person I care for has physical limitations and needs assistance with activities of daily living which is difficult for me to provide, such as getting dressed, washing, mobility, eating.	
12. The person I care for shows behaviors which are challenging for me to cope with.	
13. I cannot leave the person I care for alone for an hour.	
14. The person I care for has changed for the worse due to their condition.	
15. I experience a lot of conflict and arguments with the person I care for..	

Total

4. General challenges

16. I am burdened by other stressors in everyday life outside of my caregiving role.	
17. I experience physical health challenges on a daily basis.	
18. I am worried about my financial situation.	
19. I neglect my own health and well-being.	
20. I feel like I cannot keep up with the many demands in my everyday life.	

Total





Date	Code	Counselor
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Resilience and Strain Questionnaire for Caregivers of People living with Dementia (RESQ-CARE-DEM)

Dear family caregiver,

Caring for a person living with dementia changes one's everyday life. Family caregivers deal with this new situation in different ways. While there are some who recover from stress quickly, the majority of family caregivers are at risk of developing physical and/or mental health problems themselves due to the additional stress. This risk depends on various factors, but especially on one's own resilience, social support, and the dementia-related burden.

The aim of this questionnaire is to find out how your current situation is influenced by these positive or negative factors. Based on your answers, we want to be able to offer you optimal advice/support that is tailored to your needs. For this purpose, it is important that you answer the questions based on your current situation. Please look back over the last four weeks when answering. Your answers will be treated confidentially.

My personal information

Age	Years	
Gender	<input type="radio"/> Female <input type="radio"/> Male	<input type="radio"/> Other
Relationship to person living with dementia (I am the ...)	<input type="radio"/> Spouse <input type="radio"/> Parent	<input type="radio"/> Child <input type="radio"/> Other:
Living situation	<input type="radio"/> Together with the person living with dementia <input type="radio"/> Alone	<input type="radio"/> With one's own family, partner <input type="radio"/> Other:
Highest educational attainment	<input type="radio"/> Primary school <input type="radio"/> High school <input type="radio"/> University	<input type="radio"/> Postgraduate <input type="radio"/> No qualifications
Occupation	<input type="radio"/> Retired <input type="radio"/> Part-time <input type="radio"/> In training/studying	<input type="radio"/> Unemployed <input type="radio"/> Full-time
Time spent on caregiving	hours/week	

Information on the person living with dementia

Age	Years	
Gender	<input type="radio"/> Female <input type="radio"/> Male	<input type="radio"/> Other
Living situation	<input type="radio"/> Lives at home	<input type="radio"/> Lives in an institution





My strength-givers

1. My inner attitude

	Strongly agree	Agree	Disagree	Strongly disagree
1. I voluntarily and deliberately chose to take on the role of being a caregiver. For example, if the person living with dementia had other support options, I would still have chosen to take on this role.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Through the demands of caregiving, I am discovering new, positive sides of myself, of the person living with dementia, and/or of our relationship with each other.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. I recover quickly from stress.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. I feel competent in the care I provide. For example, I have gathered information about the condition of the person living with dementia and support services available to them.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. I am able to rely on my abilities in difficult situations.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

2. My sources of energy

	Strongly agree	Agree	Disagree	Strongly disagree
6. Despite the increased demands, I manage to pursue my own interests (such as hobbies, sport).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. I involve other people in the care I provide (e.g., family members, friends, community support services, or private support services).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. I receive positive feedback for the care I provide my care recipient (e.g., from the person living with dementia, a family member, friend, or healthcare professional).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. I have people I can always rely on.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. In my day-to-day life, I experience feelings of joy.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

My strength-sappers

3. Difficulties in managing the person living with dementia

	Strongly agree	Agree	Disagree	Strongly disagree
11. The person living with dementia has physical limitations and needs assistance with activities of daily living which is difficult for me to provide, such as getting dressed, washing, mobility, eating.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. The person living with dementia shows behaviors which are challenging for me to cope with (e.g., hallucinations, aggressive behavior, tendency to wander, (nighttime) restlessness, lack of interest).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. I find it difficult to be with the person living with dementia in public (fear of embarrassing situations, lack of understanding, loss of control).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>





14. It really bothers me that the person living with dementia has changed and I therefore have to take on more responsibility.
15. I experience a lot of conflict and arguments with the person living with dementia.

4. General challenges

- | | Strongly agree | Agree | Disagree | Strongly disagree |
|--|-----------------------|-----------------------|-----------------------|-----------------------|
| 16. I am burdened by other stressors in everyday life outside of my caregiving role (e.g., my own health and well-being, worries about other family members, finding balance with caregiving-family-work). | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 17. I experience physical health challenges on a daily basis (e.g., pain, shortness of breath, unwanted weight change, heart palpitations, dizziness, or problems with my muscles, joints, or bones). | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 18. I am worried about my financial situation. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 19. I neglect my own health and well-being (e.g., missing medical appointments, experiencing a lack of sleep, eating poorly). | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 20. I feel like I cannot keep up with the many demands in my everyday life. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

I'd like to add the following comments:

Many thanks for filling out the questionnaire!





Date	Code	Counselor
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Resilience and Strain Questionnaire for Caregivers of People living with Dementia (RESQ-CARE-DEM)

– Evaluation –

1. For orientation, evaluate the sociodemographic characteristics of the family caregiver

	No	Yes
Female gender	<input type="radio"/>	<input type="radio"/>
Low educational attainment	<input type="radio"/>	<input type="radio"/>
Co-residence with person living with dementia	<input type="radio"/>	<input type="radio"/>
More than 21 hours/week spent on caregiving	<input type="radio"/>	<input type="radio"/>
Does the total of YES answers amount to 4?	<input type="radio"/>	<input type="radio"/>

If all four criteria are present, the family caregiver belongs to a special risk group.

2. Assign the following scores to the answers

Strongly agree	Agree	Disagree	Strongly disagree
3	2	1	0

To do so, you can use the original questionnaire and note the respective scores next to the answers.

3. For each scale, check whether the following rule is fulfilled

Scale	Rule	Rule fulfilled?	
1. My inner attitude	Strongly disagree or Disagree to at least 2 questions	<input type="radio"/> Yes	<input type="radio"/> No
2. My sources of energy	Strongly disagree or Disagree to at least 2 questions	<input type="radio"/> Yes	<input type="radio"/> No
3. Difficulties in managing the person living with dementia	Strongly agree or Agree to at least 2 questions	<input type="radio"/> Yes	<input type="radio"/> No
4. General challenges	Strongly agree or Agree to at least 2 questions	<input type="radio"/> Yes	<input type="radio"/> No





If, for 3., at least 2 questions on the resilience scales were answered with Strongly disagree or Disagree and/or at least 2 questions on the stress scales were answered with Strongly agree or Agree, the counseling themes corresponding to the scale should be suggested.

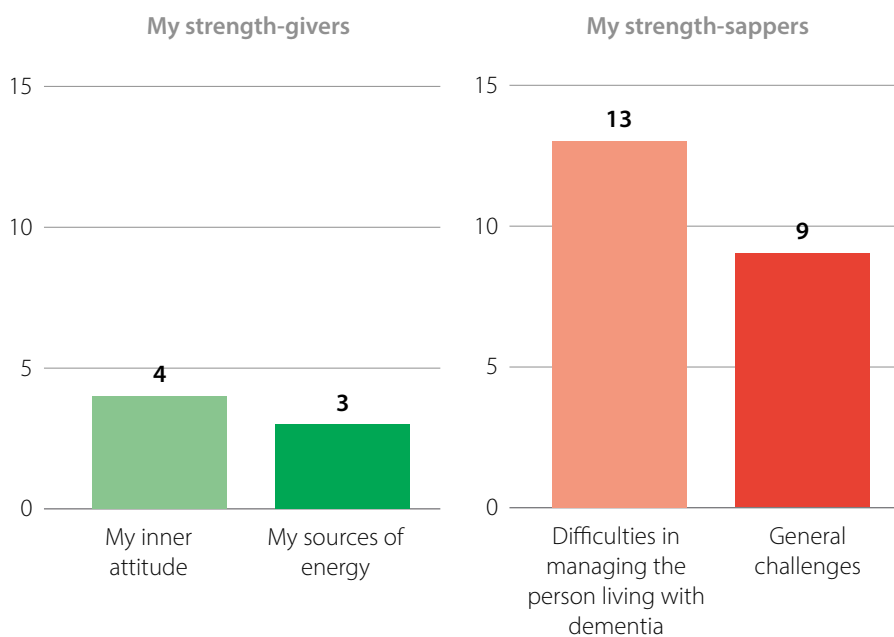
If, for 1., all questions were answered with Yes, counseling should be offered even if the aforementioned cut-off scores were narrowly missed (see manual).

4. Identify the counseling themes

Scale	Counseling themes	Recommendation
1. My inner attitude	Self-care	<input type="radio"/>
	Stress management	<input type="radio"/>
	Problem-solving training	<input type="radio"/>
2. My sources of energy	Possibilities to relieve burden (e.g., day care, in-home care)	<input type="radio"/>
	Self-help groups	<input type="radio"/>
	Self-care	<input type="radio"/>
3. Difficulties in managing the person living with dementia	Psychoeducation	<input type="radio"/>
	Psychoeducation on behavioral and psychological symptoms of dementia	<input type="radio"/>
	Refer person living with dementia to specialist physician	<input type="radio"/>
	Self-help groups	<input type="radio"/>
4. General challenges	Aspects of social welfare law (possibly debt counseling)	<input type="radio"/>
	Medical/psychiatric/psychotherapeutic assessment/diagnosis of the family caregiver	<input type="radio"/>

5. Transfer the scores for the individual answers to the Excel sheet to obtain a visual evaluation of the questionnaire

Example of visual evaluation





Resilience and Strain Questionnaire for Caregivers of People living with Dementia (RESQ-CARE-DEM) – Evaluation –

Instructions for filling out RESQ-CARE:

Please enter here the numerical value that the family caregiver gave for each question.

The answers are scored as follows:

Strongly agree 3 Agree 2 Disagree 1 Strongly disagree 0

You can then see a visual display of the results in the next spreadsheet, „The evaluation“.

My strength-givers

1. My inner attitude

1. I voluntarily and deliberately chose to take on the role of being a caregiver.	
2. Through the demands of caregiving, I am discovering new, positive sides of myself, of the person living with dementia, and/or of our relationship with each other.	
3. I recover quickly from stress.	
4. I feel competent in the care I provide. For example, I have gathered information about the condition of the person living with dementia and support services available to them.	
5. I am able to rely on my abilities in difficult situations.	

Total

2. My sources of energy

6. Despite the increased demands, I manage to pursue my own interests.	
7. I involve other people in the care I provide.	
8. I receive positive feedback for the care I provide my care recipient.	
9. I have people I can always rely on.	
10. In my day-to-day life, I experience feelings of joy.	

Total

My strength-sappers

3. Difficulties in managing the person living with dementia

11. The person living with dementia has physical limitations and needs assistance with activities of daily living which is difficult for me to provide, such as getting dressed, washing, mobility, eating.	
12. The person living with dementia shows behaviors which are challenging for me to cope with.	
13. I find it difficult to be with the person living with dementia in public.	
14. It really bothers me that the person living with dementia has changed and I therefore have to take on more responsibility.	
15. I experience a lot of conflict and arguments with the person living with dementia.	

Total

4. General challenges

16. I am burdened by other stressors in everyday life outside of my caregiving role.	
17. I experience physical health challenges on a daily basis.	
18. I am worried about my financial situation.	
19. I neglect my own health and well-being.	
20. I feel like I cannot keep up with the many demands in my everyday life.	

Total





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